BOSTON UNIVERSITY
SCHOOL OF SOCIAL WORK

CHILDREN WITH RHEUMATIC HEART DISEASE

A Study Of The Environment And School Adjustment
Of Fifteen Patients Known to The Rhode Island
State Rheumatic Fever Program

- A THESIS -

Submitted by

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CHAPTER I

INTRODUCTION

Exposition and Purpose

This is a study of fifteen rheumatic heart patients who are known to the Rhode Island State Rheumatic Fever Program, which is administered by the Division of Maternal and Child Health in cooperation with the Crippled Children's Program. Every patient under the Rhode Island State Rheumatic Fever Program is known to the Medical Social Work Consultant, who divides her time between this program and the Crippled Children's Program.

Through a study of the medical-social records known to this department, interviews with their Medical Case Work Consultant, as well as Executives of private agencies concerned with rheumatic heart disease, namely, the Rhode Island Children's Heart Association which cooperates with the Rhode Island State Rheumatic Fever Program in planning for recreation and camp, and the Community Work Shops of Rhode Island, Inc., which renders occupational therapy if needed during the convalescent stage, and with the authorities of the schools where these patients were in attendance, the writer has endeavored to determine whether or not the amount of physical limitation had an effect upon the total life adjustment of these patients. The writer has attempted to answer the following questions:

(1) Did these patients present any behavior difficulties before onset of illness which later influenced their success or failure in adjusting to the disease and to their total life situation?

(2) Did family attitudes, background and environment affect the success or failure of such adjustment?

(3) Did this group of patients make an adequate school adjustment?

(4) Does the community offer adequate facilities for maximum readjustment of rheumatic heart patients to their life situation?

While a considerable amount of literature has been written on rheumatic fever and rheumatic heart disease, and the effect of this condition upon the patient both physically and psychologically, the writer failed to find any compilation of material concerning the school adjustment, and the facilities available in Rhode Island for maximum readjustment for a specific group of patients with this diagnosis. The writer feels that further education is essential to patients with such physical limitations, since the vocational opportunities are limited in proportion to the patient's specific limitations. Where there is a severe, or very severe, physical restriction, the patient will need to seek a vocation which will involve little physical activity, but will be in the nature of a task requiring mental effort. Therefore, the school adjustment that these patients are able to make is an indication not only of their acceptance of their physical limitations, but also of their ability to direct their lives towards vocational independence and eventually the earning of their own living and so find a place in the community. In collecting case material, consideration was given by the writer to the plan made in each case by the specific rheumatic clinic doctor and the medical social work consultant for securing the necessary medical and convalescent care for the patient, and to their concern that this care be given in a way that will give the patient the greatest physical benefit without interfering with the adjustment of the patient, not only to school but also to his home environment, associates and community.

Scope of Study, Sources of Data and Method of Procedure

The fifteen cases under consideration are known to the Rhode Island State Rheumatic Fever Program. They were selected at the suggestion of the Medical Social Work Consultant specifically because the patients were of school age, had a definite diagnosis of rheumatic heart disease, and gave a cross-section of problems typical to cases under their program. The writer also interviewed the executive of the Children's Heart Association of Rhode Island to determine that agency's influence in the success or failure in the care and adjustment of some of these patients. The writer in studying these cases considered the general life adjustment before diagnosis in comparison to adjustment from date of onset of illness to the present (January 1949). The writer considers herself fortunate to have had direct contact with two of the cases that fell into this study because they happened to be part of her student case load with the Community Work Shops of Rhode Island, Inc. from October, 1948 until the writing of this thesis. In this way, first-hand knowledge was gained about the patients, and their home and school adjustments.

The method of procedure was as follows:

(1) A survey was made of literature in the fields of medicine and medical social work particularly where these fields pertained to rheumatic heart disease in order to establish a frame of reference from which to proceed to a social study. (Bibliography appears in the appendix)

(2) A study was made of the case records of fifteen individual patients, and the schedule reproduced in the appendix was filled out on each one.

(3) Data was secured from schools which these patients attended or from the home teacher if the patient was home-bound.

(4) Each medical-social record was reviewed with the medical social work consultant of the Rhode Island State Rheumatic Fever and Crippled Children's Programs in order that method of convalescent care and all social material would be known to writer.

(5) The physical handicap of each patient was reviewed with all sources of care and interest to determine the extent of handicap, physical limitations, and adequacy of the community program offered.

(Physical handicap classified according to the criteria prepared by the American Heart Association, Inc. reproduced in the appendix)

Limitations and Values

The major limitation of this study is, of course, the small number of cases included in it. Whatever conclusions are drawn will relate only to this specific group, which is a somewhat selected group, in that each patient is of school age and each patient had a definite diagnosis of rheumatic heart disease. Every patient under the Rhode Island Rheumatic Fever Program is known to the medical social work consultant who divides her time between the Rheumatic Fever and Crippled Children's Program, Division of Maternal and Child Health. How well the medical social work consultant knows the patient depends upon the number and type of problems detected during clinical visits, and/or called to her attention by the nursing staff or some other agency interested in the family.

Another limitation that is common to many studies is the nature of the records from which this data was obtained. These records are not

written primarily for the purpose of social research, but rather as an aid to determine care under the State Rheumatic Fever Program. The medical records submitted by the doctors in the respective clinics are most complete, but emphasis is on the medical progress of the patient rather than on his social adjustment.

Past school records were not always available.

Another limitation to the study is the role of the Medical Social Work Consultant in the Rhode Island State Rheumatic Fever Program. This role differs from a medical social worker in a hospital setting, in that the medical-social worker in this program functions primarily as an executive rather than a case worker and she is the only case worker employed in this program. At present the role is that of medical-social work consultant and she spends the greater part of her time in coordination of health and welfare resources for the individual patient. Chapter III includes an explanation of the role of the Medical Social Work Consultant and demonstrates the variety of her activities and her responsibilities in the Rheumatic Fever Program.

The last, and an important, limitation to the study is the time available to the writer.

The writer believes that this study may be of value to medical social workers employed in similar setups and to the community as a whole in the following ways:

(1) By establishing a frame of reference to be used in planning service to future patients of school age with a diagnosis of Rheumatic Fever or Rheumatic Heart Disease.

(2) By demonstrating the importance of the role of medical case workers in such cases.

(3) By indicating what needs are not adequately met at present and offering recommendations for improvement in the program.

CHAPTER II

RHEUMATIC HEART DISEASE

Rheumatic Heart Disease is a disease of the heart caused by acute attacks of rheumatic fever, which medical authorities describe as an infectious allergic reaction involving the joints and the heart. The etiology of this disease is explained under the sub-heading of Causes of Rheumatic Heart Disease. The heart is a pump and consists of three main anatomical elements, one of which are the valves. After heart damage which manifests itself when an acute stage of rheumatic fever is over, there is usually some impairment of the valve, technically termed the mitral valve. Medical authorities refer to this impairment as mitral stenosis, which means valvular lesion causing an obstruction of the flow of blood through the mitral valve, or there may be defects in the leaflets of the valves forcing a backward rush of blood into the heart, which causes an enlargement of the heart. This is technically termed mitral regurgitation or mitral insufficiency. These medical terms are referred to in Chapter V, in describing the rheumatic heart conditions of some of the patients in this study.

Importance

Any disease which has victimized approximately one million of the people who, today, are living in the United States, certainly deserves the attention of every thinking man and woman.

> "Except for a relatively few children whose hearts have some congenital malformation, heart disease in the young is practically always rheumatic in origin. That this is a major problem is demonstrated by the fact that more deaths result from rheumatic heart disease in persons under twenty years of age than from

> all the following diseases taken together: tuberculosis, epidemic meningitis, measles, diptheria, scarlet fever, and infantile paralysis. . . In view of the high incidence, the cost in dollars, the burden on family and community, the problem is a serious one. It is definitely a greater menace than any other crippling disease." 1

Since this disease is such a great crippler of the youth of today it is of compelling importance, because they are the future citizens on whose shoulders our democracy will rest.

Although the picture of rheumatic heart disease is rather gloomy at present, if continued individualized treatment, both medical and social, is given rheumatic heart diseased patients, a great number will be able to enjoy happy, useful lives. But because rheumatic heart disease is an illness which by its very nature so readily provokes anxiety in the patients and their parents alike, it is very important that this be considered in any plan for treating the illness.

Meaning of the Illness to the Patient and Family

> "In medicine, as in other fields, there is considerable lag between the development of a theoretical concept of its application to concrete situations. The idea that care of the sick requires consideration of the patient as a whole is not new. It has been accepted for centuries; it has been the subject of lectures in medical schools for many years; it was made a reality by the insight and understanding of many family doctors; but only recently has it begun to be applied in practice in an organized way." 2

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1 Edward L. Bouer, "Rheumatic Heart Disease in Childhood", Hygeia, 20:270, April, 1942.

2 Ethel Cohen, "What Rheumatic Fever May Mean to a Child" Reprint from The Child, Vol. 11, No. 11 April, 1947

This organized way to which Ethel Cohen refers is being revealed in the psycho-somatic approach which stresses the relation between "psyche" and "soma". It is now known that in many instances illness is both organic and functional and that the many symptoms presented are in reality an expression of the interaction of both. "It is not that the emotional aspect must always be the predominant one but that we have not sufficiently in the past seen how it was interwoven with the others; and failure to appreciate this interrelationship inevitably results in failure of the other -- that is, intellectual and environmental -- methods of treatment when used alone."[3]

This growing recognition of coordination of mind and body and that the patient exists as a member in a family unit in a social environment is a valuable contribution of social work to treatment in the medical profession.

The experience of illness creates a situation for the individual which centers around the fundamental relationships of life and the feelings that accompany it are apt to be vivid and intense in nature. "It is not possible to regard the present behavior of an ill person as divorced from his past. Illness is one of the emergencies of life particularly well-suited to create again the original family situation." [4]

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3 Harriett Bartlett, "Emotional Elements in Illness", The Family, 21:43, April 1946

4 Eleanor Cockerill, "Adventures in Understanding", The Family, 20:155, July 1939

Literature shows that rheumatic heart disease may stir up latent psychological or emotional difficulties in the child as well as in others. The child who has rheumatic heart disease may become overdependent and invalidized, rebellious because he cannot share the play and other interests of his brothers and sisters and friends, and may be envious of them. Being "different" from the others, a child may feel insecure. Becoming ill again and again, the child may be afraid that he will never recover.

If a rheumatic condition can cause all these difficulties for a child whose home life is satisfactory, how much more can it do to a rheumatic child whose home life may be unsatisfactory? It is in this sphere that the social work profession makes one of its most helpful contributions.

Rheumatic heart literature, for example, tells of a girl, eight years old, whose rheumatic illness reactivated and intensified emotional problems that had been latent since her mother's suicide when she was three years old. Fortunately, the medical social worker and the physicians at the rheumatic heart clinic were able to recognize this girl's emotional problems, and to realize that consideration of these problems was as important to her recovery as was the medical treatment of her illness.

To the parents the diagnosis of rheumatic heart disease may mean sudden shock. An over-wrought mother believes the child will eventually die. Parents may wonder what influence this will have on their own future and this anxiety may cause a whole gamut of problems. Therefore, the meaning of illness to the individual patient and his family deserves consideration and interpretation.

Extended illness brings many serious problems to the fore. Naturally, the primary concern is getting the patient well, but for the patient of school age, school is among the first considerations. If a child is to be home-bound for a period of time and needs a home teacher, it is important that he or she has a dependable, efficient and pleasant person who will adequately prepare the child for future schooling. When the child does return to school, there is an adjustment to be made to the curriculum and the routine and a preparation to be made for the acceptance of limitations of physical activity. "The child is primarily concerned with being restored to his former place in society. For this reason the question of social incapacity, whether or not it is consciously understood by the patient, is very important." 5

The child may make poor social contacts because he has inferiority feelings due to his being considered "different". He may become socially retarded and withdrawn. On the other hand he may become hostile toward the outside world, not knowing whom to blame for his disability. There is much for him to learn in a social as well as in an educational sense. All his wishes might have found gratification in his illness and he may, upon recovery from acute illness, find it difficult to readjust to a more normal life.

Causes of Rheumatic Heart Disease

Because the clear skin, shining eyes, and pink cheeks of the rheumatic patients have long deceived both the medical profession and the pub-

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5 Bartlett Op. Cit. p.43

lic, the writer believes that some discussion on the causes of rheumatic heart disease is pertinent. Beneath this picture of health lurks one of society's most devastating enemies, a crippled heart -- the peculiarities of which are not clearly known. Despite the rapid advances that have been made in medical science in the past forty years, there is still much to be learned about the causes of rheumatic fever leading to rheumatic heart disease. Medical science points to the Hemolytic Streptococcus, carried by the blood stream as the specific organism responsible for rheumatic infection. Symptoms include: sore joints, pains and aches, fever sometimes - sometimes not, fatigue, and sometimes nose bleeds. Many factors are considered to be predisposing to the disease. It attacks children in their early formative years and adolescents. Studies show that climate may be an important factor. It is essentially a disease of the temperate zones and attacks are prevalent in the early spring or late fall. Others state that there is a relationship between this disease and environmental factors. Children who live in crowded, unsanitary houses and who suffer from poor nutrition are potential rheumatic heart patients. Still other medical authorities maintain that rheumatic heart disease is hereditary, while many disagree with this theory on the basis of its contageous entity. Whichever theory is most valid, the fact remains that this infection has a tendency to affect several members within the same family unit. Over-crowding, lack of sunlight, dampness, and other environmental factors associated with poor hygiene are believed to be potent agents. Many of these conditions were evidenced in the writer's study. Unfortunately it is sometimes difficult to recognize this infection in its early stages.

Treatment

Rest is the most important treatment for this disease. Some medicine will help, but rheumatic infection cures itself in most cases if the child can be kept at rest in bed under the doctor's supervision. Rest in bed allows the heart the greatest possible help and relief from work. It gives the child his best chance to fight the germ or infection and prevents severe damage to his heart. A heart once damaged is more apt than a normal heart to suffer more injury. After the rheumatic fever is no longer active, it is still necessary to see that the child has more rest and quiet than the other children. He may need to have rest periods during the day. The rheumatic child should have his own bed or place to sleep. He needs good, nourishing food. [6]

This does not minimize the importance of adequate medical diagnostic service and the need of diverse types of facilities for treatment and convalescent care. Acutely ill children usually can be given proper care in a hospital which has more facilities than an individual home. When the child has passed through the acute stage, institutional convalescence or foster home care may be indicated. The choice of one of these alternatives will depend upon more than the medical picture. Many factors are involved. The way the child feels about the illness and enforced long-time bed rest; the intelligence and emotional stability of other members of the family and their attitude toward the patient. The health of others in the home; the housing conditions; their capacity to understand the needs of a sick child and make adaptations for his comfort and happiness; and their willingness

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6 Children's Heart Association of Rhode Island, Inc., "Primer for Parents"

to maintain the prescription for bed rest in the absence of outward physical disability - all these are factors to be considered in planning for a patient's convalescence.

It has been generally accepted that the child thrives best within his own family and naturally this is the first choice for treatment, provided the basic facilities needed for his care are available there. But with the best will in the world on the part of the family the difficulties inherent in the care of children with heart disease are often too great for many families. In planning treatment, the medical social worker can often anticipate such a situation by her knowledge of the child and his circumstances and weigh the particular situation for each child.

CHAPTER III

RHODE ISLAND STATE RHEUMATIC FEVER PROGRAM

The Social Security Act, passed in 1935, authorized the appropriation of federal funds for services for crippled children. These funds are paid to the states after annual state plans for such services have been approved by the Chief of the Children's Bureau of the United States Department of Labor.

No definition of "a crippled child" has ever been made by the Children's Bureau. During the first five years of administering services for crippled children under the Social Security Act, the states gave major attention and care to children with orthopedic or spastic conditions but there was a growing interest among both lay and professional groups in making services available to children with other crippling conditions. The recommendation of the American Academy of Pediatrics at its regional meeting in Rochester, New York, November 1938, that heart disease should be considered a crippling condition gave special impetus to the idea that children with rheumatic fever and heart disease should be eligible for services under the crippled children's program. 1 Several state plans for rheumatic fever programs were developed soon after, and Rhode Island inaugurated their program in December, 1941. The Rhode Island Department of Health through the Division of Maternal and Child Health, and in cooperation with their Crippled Children's Program, administers a state-wide program to all children under twenty-one years of age residing in Rhode

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1 United States Department of Labor, Children's Bureau 1943 "State Programs for Care of Children with Rheumatic Fever." Social Security Act Title V, Part 2.

Island who are suffering from Rheumatic Fever or Rheumatic Heart Disease or any condition leading to Rheumatic Fever or Rheumatic Heart Disease. Under this program they are eligible for diagnositc and treatment services if they are not already under medical care, either in a clinic or under the care of a private physician. Children who are under the care of a physician who is desirous of transferring the child to the state program for care will be allowed to do so following the review of the family's history.

The state gives preference to the cases of Rheumatic Fever or Rheumatic Heart Disease who have not been under medical care and who offer a fair prognosis for rehabilitation and care. When a child is accepted on the program, he receives complete service, that is, regular attendance at one of the rheumatic fever clinics, hospitalization, or care at a convalescent or foster home, if deemed advisable by the clinic physician, medical care in the home and necessary drugs prescribed by the clinic program.

Siblings of all patients under the state program can be examined in the clinics and if in need of medical care they are referred to the state program. Children already receiving medical care can be referred to the State Clinic for diagnostic and consultation service, or can also be referred for acceptance for that care. However, a child already under private medical care is usually not accepted for care under the state program. If a child is referred for diagnosis or consultation, complete check-up is done, evaluation is made by clinic physicians, and the recommendations sent to the referring physician.

The scope of the program is state-wide. At present, there are approximately twenty rheumatic fever clinics per month. They are held in the following locations:

Pawtucket - Memorial Hospital, every Tuesday
Providence - Rhode Island Hospital, every Tuesday
Charles V. Chapin Hospital, every Thursday
St. Joseph's Hospital, last Thursday of every month
Cranston - Cranston Visiting Nurses' Association, first and third Wednesday of every month
Woonsocket - Woonsocket Hospital, second Friday of every month
West Warwick -Pawtuxet Valley Visiting Nurses' Association, third Friday of every month
Warwick - Red Cross - Apponoug, first Friday of every month
Welfare Centre, Showomet, last Friday of every month

A consultation service is available to all private physicians who wish to refer their patients for complete laboratory work and physical examination by the clinic physician. This is a free service.

Transportation, when needed, is provided by the American Red Cross, the Society for Crippled Children and Adults and also by the parents and their families.

Diagnostic and treatment services are available at all the Rheumatic Fever Clinics. Admissions are on an appointment basis. The physician who conducts the clinic is able to examine the child thoroughly and utilize any diagnostic procedures that are necessary. At the patient's first visit, he receives flouroscopic examination, electrocardiogram, X-ray, laboratory examination and also medical and social studies are done at this time. At subsequent visits all of the diagnostic procedure is available for utilization if desired by the clinic physician.

Plans for finding care:

(1) For the child who is acutely ill.

The state provides care in the hospital, or at home. The clinic physician may visit the patient at home as often as medically indicated if the child is to remain at home under supervision.

(2) For the child who needs prolonged rest in bed.

This child will be cared for at his home if it is satisfactory, or if not, in a convalescent hospital or a foster home. He will continue to have the same clinic physician follow his medical care program in whichever facility he is treated.

In cooperation with the Providence School Department, any school child found to have any indication of rheumatic fever or rheumatic heart disease upon examination by the school doctor is examined at the rheumatic fever clinic, and a record of the findings is sent to the child's family physician or to the School Department when there is no family physician.

Since the inception of the program, approximately 1300 children have been examined at the various rheumatic fever clinics but not all of them have been diagnosed to have rheumatic fever or rheumatic heart disease.

The following tables I and II show the amount of funds for the various services: [2]

Table I

July 1, 1946 - June 30, 1947

Hospitalization	$ 5,179.89
Convalescent Care	41,741.59
Foster Home Care	418.99
Medical Fees (Home Visits - Clinics)	1,005.00
Other Services (drugs, etc.)	1,007.93
Total	$ 49,353.40

2 The information in this chapter was generally gained from discussion with several members of the staff, as well as from literature obtained from the department.

Table II

July 1, 1947 - June 30, 1948

Hospitalization	$ 4,876.01
Convalescent Care	39,370.26
Foster Home Care	1,444.40
Medical Fees (Home Visits - Clinics)	6,665.00
Other Services (drugs, etc.)	1,947.74
Total	$ 54,303.46

The writer feels that these figures are important in that they show that the greatest amount is expended for convalescent care indicating the important need for facilities for convalescence. Also that more children seemed to need foster home care in the period of July 1, 1947 - June 30, 1948 as evidenced by the greater amount spent during this period indicating that a large proportion of cases seen in this period came from homes which were unable to offer the child adequate facilities and environment for readjustment.

The follow-up care may indicate the use of community agencies and for this the state has a cooperative arrangement with these agencies: Local Department of Education - for home teaching; vocational guidance and rehabilitation through the State Department of Education; Mental Hygiene through the Providence Child Guidance Clinic; Community Workshops for Occupational Therapy. Other social and welfare agencies are utilized when indicated, and there is close association with the Rhode Island Children's Heart Association.

The Children's Heart Association is a voluntary agency under the Community Fund. Some of its functions may be listed as follows:

(1) Educational and promotional to disseminate information about rheumatic fever and rheumatic heart disease through pamphlets, lectures, radio, etc.

(2) Discovery of needs of rheumatic fever and rheumatic heart patients and resources to fill these needs.

(3) Services to children with rheumatic fever and rheumatic heart disease and morale building activities through:

(a) "The Bluebird Magazine", a Public Library page, a Birthday page, Radio page, simple reader participation, activities, etc.
(b) Movies at Crawford Allen Memorial every week
(c) Camping in summer [3]

Description of Provisions For Convalescent Care

Crawford Allen Memorial is the only convalescent institution in Rhode Island primarily for children with Rheumatic Heart Disease. It is an annex to the Rhode Island Hospital and is located in East Greenwich, Rhode Island. This two-story brick building has a total bed capacity of five hundred and sixty-nine (569) and the institution admits children to age twelve. Children sent to Crawford Allen Memorial are put on complete bed rest upon admittance.

The children are placed in classes according to physical condition. The classification is as follows:

Class I - Confined to bed
Class II - Allowed to walk to lavatory twice daily
Class III- Lavatory at all times
Class IV - Allowed to lavatory and to meals
Class V - Allowed to be up all day with interval rest periods
Class VI - Allowed full activity including out-door play according to their restrictive capacity

Crawford Allen Memorial has its own school room on the ground floor and the Providence School Department allows two teachers to participate

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3 This information on Children's Heart Association was obtained in a personal interview with the Executive of Rhode Island Children's Heart Association

in the program to carry on school instruction. The children go to school in their beds, cots, wheel chairs, etc. according to their physical limitation. They are taken to the class room on elevators. For children from cities and towns other than Providence, the specific locale pays tuition for the children to be taught. This tuition is paid to the Providence School Department.

The staff at the Crawford Allen Memorial includes visiting doctors, peadiatric resident of the Rhode Island Hospital plus medical internes, nurses' aides, one play therapist, one occupational therapist and one full-time social worker.

Lakeside Home, located in Warren, Rhode Island, is sometimes used for convalescent placement. It operates under the Providence Tuberculosis League, financed by the Providence Community Fund and is specifically for tuberculosis cases. Lakeside has a fifty bed preventorium and is open the year round for children under twelve years of age. Children for whom no definite diagnosis of rheumatic heart disease is made but who are showing symptoms of potential heart disease are sent here. However, Lakeside because of its limited physical facilities can accept only a limited number.

Foster homes are utilized for children over twelve and these are secured through the cooperation of the Rhode Island Children's Friend Society, a non-profit organization under the Community Chest. The number of homes that will take rheumatic children (especially adolescent children) is small.

Summer camps are arranged through the Children's Heart Association. They arrange resident camps for cardiac children and day camps for poten-

tial rheumatic fever children. [4]

Role of the Medical Social Worker

The role of the medical social worker in the Rhode Island State Rheumatic Fever and Crippled Children's program is that of a consultant and coordinator. Her many activities may be outlined as follows:

(1) Attendance at as many clinics as feasible.

(2) Attendance at various outside committee meetings of organization who are interested or potentially interested in the patients on the above programs.

(3) Attendance at conferences in which program planning is discussed.

(4) In staff training program for the various personnel with the agency.

(5) Field visits to the various Health Units for the purpose of consultation on situations needing a social interpretation.

(6) Promotion of cooperative relationships with other agencies (health, education, welfare, rehabilitation and promotional service agencies).

(7) Offering direct service when there is no other resource available.

The many types of problems which confront the Medical Social Work Consultant are situations where family attitudes interfere with medical or

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4 Information obtained from Chief Nurse in the Rhode Island State Rheumatic Fever Program.

social situations; problems where the home situation prevents carrying out the medical recommendations; behavior problems relating to the health situation; school adjustment in relation to the health problem; convalescent care placement; referral for hospitalization; economic problems; problems concerning rehabilitation or employment or job counselling or training. [5]

Medical care in a rheumatic program needs the consideration of the total requirements of the patient to be effective. The physical, social, environmental and emotional situations must be evaluated in order that the total patient may be treated. All persons on the medical team (physician, public health nurse and medical social worker) should be concerned and share in this, but it should be the primary consideration of the medical social worker to be responsible for the evaluation of the social and emotional situations as they affect the patient under care. It should be her responsibility to bring an awareness of the above-stated factors affecting the health services and their use by the patient to the personnel, dealing directly with the patients in the various clinics.

All this promotes wider understanding of the significance of the childhood crippler and mutual effort in behalf of the child's care and adjustment. The most important special knowledge brought to the situation by the medical social worker is how to correlate the implications of the person's illness with his personal and environmental problems.

The extent to which disability is actually disabling varies from person to person. It depends upon the attitude of the patient, his age,

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5 Information on role of medical social worker obtained directly from Medical Social Work Consultant in Rhode Island State Rheumatic Fever and Crippled Children's Programs.

the attitude of those around him, his scholastic preparation and the goal he has set for himself. It is here that the medical social worker makes her greatest contribution although this may not be done through direct service.

CHAPTER IV

SCHOOLS

The writer believes that some description of the school situation of these fifteen patients in this study is necessary in order that the circumstances under which these patients receive their education may be better understood. There was no common factor in the schooling of these patients. Three were in parochial schools, seven in public schools, two were in state institutions, two on home teaching program, and one had not started school.

It is to be kept in mind that the public schools are set up for the child who is without physical or mental handicap. The children in this study are expected to make a satisfactory adjustment in an environment that is not primarily adapted to their limitations.

At the time of this study, R. R., age 6, had not yet entered school. A. B., was in the second grade in a parochial school, Providence, at the time of diagnosis. She is now in the third grade in the same parochial school. E. G. was in the third grade in a parochial grammar school in a small town outside of Providence at the time of diagnosis two years ago. She is presently on the home teaching program and is receiving instruction once a week. J. O. and E. O., brothers, were in the same public school system in a small community outside of the city of Providence. J. O. was in the third and E. O. was in the fifth grade at age 14, because this area did not offer ungraded class program. He is mentally below par and his retardation was not due to the period spent in convalescence. J. M. was not of school age at the time of onset. She is

presently on home teaching service and is receiving instruction once a week. D. H. was in the sixth grade in a large public school in Providence at the time of diagnosis. At the time of this study she was in a public school in an ungraded class. A. T. was in a parochial school at the time of diagnosis. According to school authorities she had always been a behavior problem. After onset she was sent to the State Home and School and finally to a Catholic Training School for girls. R.D. and C. R. were attending a small rural public school at the time of onset respectively. R.D. was retarded mentally and had repeated the first grade three times. Following convalescence he was committed for a period of one year to the Exeter School, a training school for mentally retarded boys. A.M. was attending a parochial academy and was in the tenth grade at the time of diagnosis. She was being prepared in the commerical course. After convalescence she returned to the academy where the facilities were such that she could take all her studies on the first floor. E.H., at the time of diagnosis, was in the sixth grade in a public school in the city of Providence. At the time of this study she had been placed on the home teaching program and was awaiting assignment of a home teacher since the School Department has a limited number of home teachers. A.G. was attending a public school before illness and was in the fourth grade. At the time of this study she had returned to the same public school and was in the seventh grade. K.M. was attending a public school in a suburb of Providence. At the time of diagnosis he was in the third grade. He had no interest in school and referal to the Child Guidance Clinic was being considered and carried out. After convalescence he returned to the same school and at the time of this study was in the seventh grade. J.O'N. was thirteen at the time of diagnosis and attending the sixth grade in

a public school. At the same time she was being seen in the Child Guidance Clinic because of unhappiness in the home. After six months' convalescence in a foster home she transferred to a parochial school. Previous to onset of the illness and when she returned to school following convalescence, school authorities found that she did average work and seemed to like school. However, unhappy conditions prevailed at home, aggravating her health, and through cooperation with the Rhode Island Children's Friend Society, plans were made for placement at the Children's Center, New Haven, Connecticut.

Four of the fifteen patients had received some instruction at the institution in which they had been placed during convalescence, i. e. Crawford Allen Memorial and Lakeside and therefore did not miss any school work.

While the medical social work consultant and the school departments realized that these children were either facing retardation or further retardation because of long time treatment and convalescence, no definite methods were employed to elicit the child's best efforts for school adjustment. The schools were not physically equipped to meet the needs of the children returning to school. The community could offer no transportation facilities to the more physically limited patients. Only two of the schools where these patients were in attendance had a full-time school nurse. One patient who was placed on the home teaching program because of her physical limitation was waiting for assignment of a home teacher because the specific community has a limited number of home teachers.

CHAPTER V

PRESENTATION OF CASES

Introduction

The writer considered four factors in each case, as influencing the adjustment of these patients. These were: (1) consideration of behavior difficulties and problems in the home before onset of the rheumatic heart condition; (2) the age of the patient at the time of onset of illness; (3) the period of hospitalization and the provision for convalescent care; (4) the extent of physical limitation. Of these four factors the extent of physical limitations appeared to the writer to have the least effect upon the school adjustment, as shown in Chart I in the appendix. This does not imply, however, that the physical limitation has had no effect upon the total adjustment of these patients. Potential sources of social difficulties exist in the very nature of rheumatic heart disease itself: in the sudden danger of its acute phases, in the possibility of recurrence and progression and in its chronicity. The fear and anxiety expressed by the parents and the patients, separation from the family, both in the hospital and later in institutions have been experiences which the patients will not forget, and in complement with the emotional influences in their environment before onset, have influenced their ability to adjust, not only to the school which they attended but also to their families, their friends and to their small or large communities.

The cases were classified in three groups according to the first three factors presented in the hypothesis. Group I will include those patients who presented behavior difficulties before onset that influenced the success or failure of adjustment. Group II shows the effect of family attitudes, background and environment in the success or failure of adjustment. Group III will represent the patients who show factors which prevent an adequate school adjustment.

The fourth question in the hypothesis regarding community facilities for readjustment will be considered in the presentation of cases falling into each of the above three groups.

Characteristics of the Patients Studied

There were nine girls and six boys in the group of the fifteen patients studied. All the patients were white, native born and had a definite diagnosis of Rheumatic Heart Disease. One patient was of foreign-born parents. (French Canadian).

Eight came from homes where incomes averaged from $35 to $40 weekly, three from homes where incomes averaged $40 to $45, one from a home where the income averaged $30 to $35, one from a home where the income averaged $50 to $55 weekly and two from homes of $60 to $65 where incomes were somewhat better but irregular. This is shown in Chart III in the appendix.

Seven patients were in public shcool systems, three were in parochial schools, two in state institutions and two on the home teaching program. (Chart II in the appendix shows the relationship of the age at the time of onset, and the provisions made for convalescent care with the school adjustment achieved by these patients).

Case Presentation

If a child has rheumatic heart disease it is obvious that considerable adjustment of his whole pattern of living, and that of his family

as well, may be necessary if he is to accept and benefit fully from the prescribed medical treatment, which usually includes a long period of bed rest, good diet and supervised activity.

The impact of the illness so often occurs when the individual is vigorous and needs opportunity to work off much hostility and aggression. The child may be presenting behavior difficulties which are detrimental to his care in this illness and the picture of emotional strain becomes even greater.

Group I

This group consists of five patients, two girls and three boys. Three of the cases will be presented only, to avoid duplication of the same type of behavior problems presented.

Case I - A. T. was just entering the period of adolescence at the time of the onset of the disease in 1942. All through early childhood she was temperamental, rebellious, irritable and very nervous. A. T. was a patient at the Bradley Home (a psychiatric hospital for children) from August 23, 1938 to November 23, 1939. She was referred because of poor toilet habits, petty delinquency, short attention spans, and poor learning power. Aside from being hyperactive, A. made a fairly good adjustment at Bradley and responded fairly well to the school program. When she returned home in 1939 she became defiant and sullen and developed poor eating habits. She played hard -- almost to the point of exhaustion. She became physically run down, her health began to fail, and on April 28, 1942 she became acutely ill.

She was hospitalized at the Rhode Island Hospital where a diagnosis of rheumatic heart disease, with mitral regurgitation was made. Her condition was classified as II-C which indicated a marked limitation of physical activity. She was not cooperative in any medical treatment offered and has had five hospital admissions.

On September 1, 1944, because she was not responding to treatment and because she was a behavior problem, she

was placed in a foster home through the cooperation of the Rhode Island Children's Friend Society. Her foster parents became increasingly fond of her but her behavior problems did not seem to disappear. She remained in the foster home until June 12, 1945 when her father persuaded her to return home. She became more upset and less cooperative in carrying out medical recommendations. Two days later, on June 14, 1945, she was committed to the State Home and School for one year. On September 30, 1945 she ran away from the State Home and School with another girl. This girl brought her to a friend's home where she was later picked up by a worker from the State Home and School. A. became more defiant and sullen upon her return to the State Home and on November 5, 1945 ran away again. When she was returned to the institution, she was difficult to manage and was transferred to another girls' cottage. On December 23d she ran away again after getting into mischief with a substitute matron. When returned she was unmanageable and ran away again. This time she influenced another girl to go with her. On January 16, 1946, she was sent to a Catholic Training School. She became ill again and on June 15, 1947 she was re-admitted to the Rhode Island Hospital with acute rheumatic flareup and long term bed rest was recommended. She was transferred to the State Informary on June 23, 1947 and left against advice on July 4, 1947.

The patient, now age 18, is at home with the father. The mother is deceased. The situation is poor. Home conditions are worse. The father is living with another woman to whom he is not married. There is a great deal of friction between the patient and the father. She accuses the father of not wanting to give up this woman to care for her. She does not follow medical recommendations and her prognosis is rated as poor.

This case well illustrates how behavior difficulties before onset have influenced a successful adjustment. Throughout childhood she was temperamental and rebellious. She was defiant and developed poor eating habits -- all factors which prevented carrying out of medical recommendations of a good diet, much needed rest, restrictive activity and an acceptance of her physical limitation. She has shown little change in behavior in a period of five years and it appears that this factor will continue to prevent a satisfactory physical adjustment.

Case II - R.D. was twelve years old when he became ill in 1943. Past social history shows that previous to onset both parents were present and the mother seemed to be a good mother who was accepting and had a firm affection for her family.

The patient, the fifth youngest of fifteen children, twelve of whom are living, had early presented behavior difficulties. He was over-active and began to "cut up" in the home. As a growing child, he would not sleep when put to bed for his daily afternoon nap. At age of ten he became wayward and was later sentenced for six months to the Sockanosset Training School for Boys for petty larceny. The staff observed that the boy was wilful and at times very aggressive.

At the end of the six months' period the patient returned to his home and to the public school where he was in attendance prior to sentence. School authorities report that he repeated the first grade three times, that his scholarship was poor but his teacher rated his school adjustment as good because his conduct was good. In his own neighborhood the patient was considered a "bully" and played hard.

Past medical history shows that patient was a healthy baby except for colds. When he was nine years old he complained of excruciating pains in his knees and was sick off and on but would not remain in bed or stay indoors. The family called a doctor during one of these attacks but the patient sneaked out of a window before the doctor arrived and consequently received no medical attention.

He finally consented to go with his mother to an out-patient clinic where a diagnosis of rheumatic heart disease with mitral stenosis and regurgitation was made. His condition was classified as Class II-C. The patient was ordered to bed with home supervision. The mother was unable to discipline him and he was transferred to Lakeside for convalescence. At Lakeside he refused medical discipline, began to "cut up" and ran away many times. He always went home and was brought back because his family absolutely felt they could not discipline him. At Lakeside, the medical staff observed that the patient was mentally handicapped and recommended that he be placed in the Exeter School for Mentally Handicapped Children. Through the Woonsocket Court, the patient was committed to Exeter for a period of one year. He attended junior high in an ungraded school room. He showed interest in school, but was considered a disturbing influence to the

other boys at Exeter. He would not take his rest periods and when told not to lift heavy articles, he seemd to do this deliberately.

The patient was returned to the community after the one year period but his behavior remained unchanged. The mother has become most discouraged and has lost interest in the boy because he has been unmanageable.

The patient is now seventeen years old. The father died suddenly (December, 1948) of a heart attack, making the disciplinary problem even harder. The mother feels that some type of employment might help to decrease his aggressive activity, but it is felt that employment would be a difficult situation. The medical social work consultant referred the patient to the State Rehabilitation Department, who in turn placed him at the Community Workshop of Rhode Island, to learn jewelry work. He is a disturbing influence and his attendance is irregular.

The patient is still being carried on the State Rheumatic Program and his heart condition remains essentially unchanged.

This patient is presenting many behavior difficulties which are unsuitable to a cardiac regime. Most of the difficulties were present before onset and consequently are disturbing influences to his present physical health. The patient is not accepting the seriousness of his condition which is preventing him from making a satisfactory adjustment. The writer believes that this patient's mentally retarded condition must also be taken into consideration as a causative factor in this patient's failure to modify his behavior for a satisfactory adjustment to the restrictive limitation placed upon him as a result of a rheumatic heart.

Case III - K.M. was eight years old at the time of onset of illness in 1942. Social history shows that both parents were present. The family was accepting and there were no evidences of neglect. The patient has always been a behavior problem. He exhibited many temper tantrums, was mischievous and plagued the other children in the home.

Prior to onset the patient was in the third grade. He showed no interest and his adjustment was considered as poor. The teacher described him as "full of animal spirit" and requested referal to the Child Guidance Clinic, which was accepted by the family. The boy would be destructive in the waiting room of the clinic and it was difficult to keep him in treatment. He became defiant at home and refused to take his meals.

His condition was diagnosed as early rheumatic heart disease, with a murmur over the mitral area. His condition was classified as I-B with prognosis good, provided activities could be curbed. Since home conditions were favorable, recommendations were made that he be supervised in the home where he was loved and accepted. All activities were to be curbed and the patient was not to go to school.

The mother was intelligent and concerned. He was difficult to keep in bed. He became very hostile and refused to eat unless he could get up. Despite his behavior difficulties, the mother continued to give him attention and care, but his condition became painfully worse. He would kick and shout and threatened to jump out of the window unless he was allowed to go out of doors. He was hospitalized for two months where he was given an opportunity to see other children in his same condition. His parents visited him daily.

When he returned home he became over active and aggressive again and suffered another attack. Another attempt was made to have him treated at the Guidance Clinic and some modification of behavior was effected. He returned to school and the teacher reported that he was doing fairly well and his school adjustment was rated as good. At home, although less of a problem, he would not accept the medical care outlined for him and his behavior difficulties continued to influence the success of his physical progress.

At the end of the school year through the Rhode Island Children's Heart Association, arrangements were made to send him to a summer camp under the Y.M.C.A. This was a favorable experience for him. He became neat and mindful and very eager to improve.

At the time of this study, the patient was fifteen and still in school. He had a burning desire to become a junior camp counselor under the Y.M.C.A. but his request was rejected because of his physical limit-

ation and lack of training. He has once again become overly aggressive and is developing a mutilated personality, which in turn is a preventive factor influencing a successful adjustment.

This case not only shows that behavior difficulties before onset influence physical adjustment, but also that the community can serve as a contributing factor when it is unable to meet a youth's needs because of specific limitations.

Group II.

Seven were classified in this group, six of whom were girls. The following case illustrates how family attitudes and a disturbed family background is preventing a good physical and emotional adjustment. This case is representative of four other patients in this group where the same type of problem existed.

Case I.- A.G. now age ten, is one of four children. Her family situation according to the medical social record is not a very satisfactory one. Her parents separate every once in a while. There is a great deal of friction among them. The mother is self-centered, and goes out on drinking parties. The father is the effectual one. Their attitude toward A. is somewhat passive and as a result A. is over-active and wilful. When the family is together they occupy a second floor, five-room apartment which is adequate from a physical standpoint. The father does wood-work and averages $40 weekly when employed and they are just able to manage. They live in a poor neighborhood. The father also drinks and constantly runs up debts.

The children have been placed in the St. Frances Orphanage each time the parents separated. When A. was first taken ill on March 20, 1946, she was living at the Orphanage. She entered the Woonsocket Hospital where a diagnosis of rheumatic heart disease was made. According to the medical record, her condition was classified as II-C with activity quite limited. Because of the lack of interest on the part of the mother and her pre-occupation with herself, it was felt that she was psychologically unsuited for caring for this child. Consequently after a six weeks' period of

hospitalization, she was placed in a foster home. The case worker of the Rhode Island Children's Friend Society stated that patient was happy in this home and seemed to have made a favorable adjustment. However, this placement was only for a convalescent period and she was returned to her home after convalescence.

Her parents are inconsiderate and do not seem to care whether or not patient follows the prescribed medical routine. They falsely reassure her about her condition and the mother is insistent that she help in the home.

She does not enjoy being home with her parents and looks forward to going to school each day. School authorities report that she is well liked by her classmates and consider her adjustment as good.

Physically she is receiving poor supervision at home, which is a strong determinant in her slow physical progress. She feels that her parents are neglecting her and wishes she could return to her foster parents.

This child, who has been continuously subjected to a broken home, was taken ill when she was eight years old. She shows indications of a child who has been seriously hurt emotionally by her parents. There is a very real problem in the home, influencing the physical adjustment and much needed care. The mother seems to be interested in her own good time and is not accepting the fact that this child has rheumatic heart disease and is in need of a cardiac regime and emotional assurance. The father is the effectual one but is not too competent as a father. Although the home is adequate from the physical standpoint, friction and the unfavorable attitudes within the family are contributing factors in preventing a successful adjustment of this child to her physical and emotional needs. Unfortunately, she could not remain in the foster home. The only case work help that this child is receiving is under the State Rheumatic Fever Program.

Case II - J.O., now age eight, is one of twins who are the second youngest in a family of nine living children. The other twin is well. A younger sister has potential heart disease of rheumatic origin. An older brother also has a rheumatic heart condition and will be discussed later.

The family live in four rooms on the first floor of an old building in a poor neighborhood. The home is crowded, poorly furnished, very damp and in need of repair. The father was an unskilled laborer until his sudden death, November 1947 of a rheumatic cardiac condition. The mother's health has suffered from lack of food, anxiety, worry and many pregnancies. Since the death of her husband she has gone to work, leaving the children in the care of the maternal grandmother. The income is being supplemented by a Family Welfare Society.

Past medical history shows evidence of the patient having had rickets in early infancy. The patient had a severe attack of rheumatic fever early in 1947. On August 18, 1947 he suffered a second attack which was diagnosed as rheumatic heart disease, mitral regurgitation. His condition was rated as II-C, indicating limitation of physical activity, and whose more strenuous habitual efforts should be discontinued.

The patient was hospitalized for a short period and because of the physical inadequacy of his home was placed in a foster home for convalescence. He was returned to his home after seven months. The worker was anxious to have him return home because his mother needed reassurance that authorities were not trying to take her children away from her and because J. had only remained in the foster home to complete the school year.

Since his return home, the mother is babying him a great deal. She is not financially able to provide the good rounded diet prescribed for him. As a result of the mother's over-protection, he is now very much the complaining babyish child who wants his own way. At school he is doing poor work as compared to prior to onset and does not get along with the other children in the class. The teacher describes him as being over-sensitive and feels he is capable of better work.

According to the medical-social record, the patient is not getting the proper rest because of poor sleeping arrangements. Medical recommendations for a well-rounded diet are not being carried out, not because of a lack of interest by the mother but primarily because she feels that she must buy food that will stretch a long way.

The above case was selected in comparison to the preceding one to show how over-protective attitudes and what appears to be a mother's firm affection for a child can be a causative factor preventing a successful adjustment post convalescence. Obvious in this case of course, is the physical inadequacy of the home and the marginal standard of living, two elements which prevent any optimum realization for prescribed medical care.

In analyzing this case, the writer noted too, that it is representative of two of the scientific theories of causes of rheumatic heart disease discussed in Chapter II, namely that there is (1) a relationship between this disease and environmental factors and that (2) this condition may be hereditary.

Case III - J. O'N. now eighteen, is the oldest of eight children. The family reside in a six-room apartment in a new housing project. Although adequate from a physical standpoint, the home shows signs of laxity in management. The father is employed as a time keeper and averages $42.80 weekly. The father and mother are congenial but disagree over the question of children. Because of religious background, the father refuses to let the mother practice birth control, which is a constant worry to her. The mother is emotionally immature and unburdens her problems of pregnancies to J. Much of the household responsibilities have fallen to her. J. has a strong attachment to her father and has assumed the role of mother toward the children rather than daughter-to-father relationship.

J. was taken ill at age thirteen eary in 1943. Her condition was classified as Class II-C, with mitral regurgitation. At the time of onset, it was observed that patient was a desperate little girl, unhappy but could not understand her unhappiness. The medical case work consultant felt that the responsibilities in the household were too great for a child in her physical condition and arrangements were made for foster home care during convalescence. J. was accepted for placement by the Children's Friend Society with the recommendation that an occupational therapist work with J. because she was unhappy, could not attend school, and

needed to be interested in quiet pursuits. J. was placed April 12, 1943 and replaced April 16, 1943 because her father and mother objected to the cold which J. got immediately after placement. J. made a good adjustment in this home and gained 8-1/2 pounds. All during her stay her parents and especially her father kept insisting that she be returned home as they thought she was home-sick. At their insistence, although against medical advice, she returned home August 2, 1943. J. returned to St. Joseph's Parochial School and did average work. She received "A" in conduct and effort.

Children's Friend Society attempted supervision of J. in her home but received no cooperation from the family. Her parents, particularly her mother, became impatient and demanding. Her physical condition was poor and there was no improvement in her heart condition.

Dr. B. talked with her at the Child Guidance Clinic. He found that "she was a very unhappy child who talked about death, getting killed and so forth." He questioned whether or not there was a reversed Oedipus situation between J. and her father. He felt that the father was very attached to her and that an unhealthy situation existed, possibly "unconscious seduction". He felt that the basis of J's own fears lay in the mother's expression that J. would become sex delinquent.

On April 17, 1944 a conference was held at the Child Guidance Clinic with all active agencies present. It was decided to remove J. from the home and place her in an institutional set-up which could look into both her health and emotional problems. It was unanimously felt that the emotional influences in the home were severely hindering any chance for physical improvement.

The community could not offer any institution that would consider a girl of this age and some effort was made to place her at the New England Home for Little Wanderers. There was no vacancy and it was suggested that the Children's Friend Society contact the Children's Center, New Haven, Connecticut. The Center accepted her and she remained there until August 31, 1947 at which time she was returned home against advice but because of the insistence of her parents.

Records from the Children's Center state that she responded in some degree to the institution. On the whole, she fitted in quite well, which was not true at first. She had taken on some ideals for herself in regard to behavior and standards of living. On the

> Stanford Binet, her I. Q. was determined at 112. They felt that this girl had real potentialities, but because of the conditions at home, it was doubtful that she would make any adequate adjustment.
>
> Because of the poor prognosis and other things mentioned, the Children's Friend Society felt that they would be unable to do anything constructive for the girl and closed their contact.

This case illustrates that of equal importance with the child's physical surroundings are the persons in immediate contact with the patient. During the early formative years the child is particularly susceptible to the emotional influence in his environment. Friction, unhealthy attitudes and other tensions as evidenced in J's home may have an adverse psychologic effect of far-reaching consequence on the child's entire later life.

At the time of this study J. was back in the community and has obtained employment as a waitress -- a job which is taxing her physical condition.

Conditions in the home are unaltered and physical improvement under such conditions seem unlikely even after the most ideal hospital care. This mother is not emotionally equipped to meet this patient's needs and the father is a strong factor in J's life.

Considerable social case work, based on understanding of the emotional reactions of the members of this family is required before this patient can ever receive adequate care in the home.

Group III

This group includes three patients, two girls and one boy.

"Worries over school retardation are common among patients. In the early period, promise and explanation of the home teacher's service,

and of the auxiliary educational services, are reassuring."[1] It is an accepted thing for each child, when he reaches the proper age, to go to school. This gives him the feeling that he is part of society. A child who is ill or convalescing may feel a real deprivation if he is not allowed to participate in the daily activity of going to school with his friends. Such was the case of two of the patients in this study, and will be illustrated by the following case.

Case I - E.H. age twelve, is the third oldest in a family unit of six children. Both parents are present, kind and accepting. The father works steadily for a hair-dressing company.

A diagnosis of rheumatic heart disease was made on May 16, 1946 when E. was nine years old. Her condition was classified as I-B with mimimal cardiac complications. She was not progressing well at home and her parents consented to placement at Crawford Allen Memorial. She remained there for a period of eleven months. E. seemed to enjoy her stay, progressed nicely, looked forward to the school instruction, but expressed much anxiety about wanting to return to school and fear about not being promoted.

Post convalescence she resumed her studies in the same public school, worked hard and picked up her work rapidly, but physically she was unable to continue. The rheumatic fever clinic physician said that she was overexerting herself with school work and advised that she leave school for the present.

She is presently on the waiting list for a home teacher and because of this is worrying a great deal about school, is losing her appetite and becoming very restless. She is presenting a disciplinary problem to her parents and the medical social work consultant is referring her to the Community Workshops of Rhode Island for occupational therapy in the home until a home teacher is available.

This case shows that the effects of loss of school work can be a serious element in the success of physical progress. This is not typical

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1 Virginia B. Ebert, "Case Work Service to Children with Rheumatic Heart Disease", The Family, 22:13 March, 1941

of most of the cases in the study. The extent of the physical limitation appeared to the writer to have the least effect upon the school adjustment of the patients.

In view of the fact that E. is on the waiting list for a home teacher, is an indication that the community does not adequately meet the educational needs in this area.

> Case II - E. O. brother of J. O. discussed under Group II, was in the fifth grade at age fourteen. He was made fun of by the other students and the teacher scolded him often for not holding interest in the daily class room instruction. According to the case record he spoke of "being shut in" in school.
>
> When he became ill, he became active, restless and apparently unaware of his physical condition. The doctor advised a home teacher, because psychologically it would be better. He was going to school with children younger than he was.
>
> A home teacher went into the home, but would not accept the patient for home teaching because the home was too dirty. She advised that he return to school. At this suggestion the patient became ill again. He developed choreiform movements, anxiety and remained in bed. There were expressions of negativism and hostility.
>
> The medical case work consultant offered him a plan for occupational therapy at the community workshops. He chose this in preference to returning to school.

The above case demonstrates the fact that school can be a harmful experience if the teacher of the patient does not have understanding nor the knowledge regarding the illness suffered by the patient. It is unfortunate that a dirty home can prevent home instruction.

The writer believes that choreiform movements may become a habit or a reaction to a threatening situation with which the patient cannot cope. In this situation the threat lies in the school experience and can be considered a causative factor in the failure of adjustment for this

patient. It was evident that the patient was not up to par, and could have been spared a great deal of anxiety if the community could have offered him schooling in a special class.

CHAPTER VI

SUMMARY AND CONCLUSIONS

Restatement of Purpose and Values

This study of fifteen rheumatic heart patients was undertaken to answer the following questions:

(1) Did these patients present any behavior difficulties before onset of illness which later influenced their success or failure in adjusting to the disease and to their total life situation?

(2) Did family attitudes, background and environment affect the success or failure of such adjustment?

(3) Did this group of patients make an adequate school adjustment?

(4) Does the community offer adequate facilities for maximum readjustment of rheumatic heart patients to their life situation?

The values of this study, as they appeared to the writer, and as stated in the Introduction, were:

(1) Establishing a frame of reference to be used in planning service to future patients of school age with a diagnosis of Rheumatic Fever or Rheumatic Heart Disease.

(2) Demonstrating the importance of the role of medical case workers in such cases.

(3) Indicating what needs are not adequately met at present and offering recommendations for improvement in the program.

Summary

Before interpreting the data secured through examination of the records studied, a discussion of the meaning of illness to the patient

and family was presented. Following this was a description of the physical factors involved in rheumatic heart disease as well as a description of the Rhode Island State Rheumatic Fever Program and the role of the medical social worker in this program. It was felt that background material was essential for the better understanding of the cases.

In the group of fifteen patients studied, there were six boys and nine girls. All the patients were white, native-born and had a definite diagnosis of Rheumatic Heart Disease. One patient was of foreign born parents (French Canadian). Eight came from homes where incomes averaged $35 to $40 weekly, three from homes where incomes were $40 to $45, one from a home where the income averaged $50 to $55 weekly, and two from homes of $60 to $65 where incomes were somewhat better but irregular.

Seven patients were in public school systems, three were in parochial schools, two in state institutions and two on the home teaching program. The writer does not feel that the heart condition in and of itself has had any measurable effect upon the school adjustment of these fifteen patients. With the exception of the three patients discussed in Group III in which school was a factor influencing the patient's adjustment, all other patients in this study were able to accept returning to school or home teaching. A case under the discussion in Group III illustrates that a child can suffer a great deal if the teacher does not have understanding nor the knowledge regarding the illness of the child and what it means to him.

The extent to which family attitudes, friction, background and environment influenced the success or failure of adjustment was dis-

cussed in Group II. In analyzing the cases in this group the writer pointed out that of equal importance with the patient's physical surroundings are the persons in immediate contact with them. Two of the cases presented showed that friction, unhealthy attitudes and other tensions may have an adverse psychologic effect of far-reaching consequence on the child's entire later life, and since a child with rheumatic heart disease is considered to have a lifetime problem, it is of compelling importance to consider both the physical needs, the family attitudes and background of the patient.

The five cases that were discussed under Group I illustrated how behavior problems prior to onset were detrimental in the progress of adjustment of these patients, despite the fact that they were loved and accepted by their families. The fact that the community could not always meet their needs is a point for consideration.

Conclusion

All fifteen patients in this study had some emotional or social problems which affected their adjustment to the treatment recommended. With the exception of the three patients discussed in Group III in which school was a negative factor in the patients' general adjustment, all other patients in this study were able to accept returning to school or home teaching. In the case presentations, the writer pointed out that a child can suffer a great deal if the teacher does not have adequate knowledge regarding the illness and what it means to him. Seven patients, six of whom were girls, were unable to make an adequate adjustment because physical conditions and emotional influences in their respective

homes were severely hindering any chance for physical improvement. Five patients, three of whom were boys, presented behavior problems before onset of illness which were disturbing influences to their prescribed cardiac regime. Thus, it would appear that behavior difficulties previous to onset were of paramount significance in the success or failure of adjustment of the fifteen rheumatic heart patients studied. That the heart as the core of the individual's life can not be over-emphasized and therefore individualized evaluation of the patient in all of his significant relationships should be the focus if any treatment plan is to be effective. The objectives for care of such patients can only be accomplished with the reduction of behavior difficulties that influence progress. Only then will the patient be able to rise above his disability and palliation of the distress. These objectives have their chance in the clinics and hospitals where physicians and medical social workers function together in assisting the patient to meet his problems. The fact that the role of the medical case worker in the Rhode Island State Rheumatic Fever Program, is that of a consultant, and the fact that she divides her time between this program and the Crippled Children's Program, allows her to render only a limited amount of much needed case work service.

Environmental conditions of dampness, overcrowding, general poor hygiene and inadequate nutrition seem to be contributing factors in preventing an adequate physical adjustment. It seems that this is a disease of the poor, but not the very poor. Why this is so was not the basis of this study, but might be investigated in further study. There seemed to be a real need for convalescence out of the home for most of these patients.

The degree of family disturbances as influential factors shown in the cases presented seems to indicate that some sort of case work would be valuable in the home. This, the writer realizes, is not always possible under the Rhode Island State Rheumatic Fever Program, as the medical social worker's role is primarily that of a consultant and coordinator. However, referral to case work agencies is possible and could be used more often, with the medical case work consultant giving consulation and reviewing progress of the patient both medically and socially with the case work agency at frequent intervals. Also, the schools themselves need the consultation of the medical social worker so that they will better understand rheumatic heart disease and its emotionally and physically crippling effects. This would certainly point the way toward a more thoughtful approach on the part of home teachers.

That the community is not able to offer adequate facilities to these patients is recognized. The community has no facilities for adolescent care. Crawford Allen Memorial takes a few for convalescence but it does not take care of all who would benefit.

The Providence School Department has a limited staff of home teachers and there are areas where no home teaching is available. Ideally, would be a plan for transportation to the Mary C. Green School, Providence, which offers facilities to physically handicapped children. At the time of this study some reference was made by the staff of the Rhode Island State Rheumatic Fever Program and the Providence School Department to such a plan. However, only those patients who reside in Providence would benefit if worked out with the Providence School Department alone.

Camp is a good experience for these patients so that they do not become cardiac conscious. Last year only thirty-seven placements were possible. This only touches the top of those who would benefit by this experience.

The writer noted also that after age twenty-one, there is no private agency or state program to help these rheumatic patients. This was not a factor in this study, but would indicate the need of further study on what can be done to improve the community facilities for the best kind of adjustment for patients with this diagnosis.

In conclusion, it may be said that medical care alone is inadequate, and is economically wasteful unless at each step there is study and active case work planning to meet the child's emotional and social needs.

Approved,

Richard K. Conant

Richard K. Conant
Dean

A P P E N D I X

SCHEDULE

Name: Date of Birth: Sex:

Address:

Religion:

Nationality: Color Foreign-born Parents

Family Situation

Parental situation -
Parents separated, step-parent, foster parents, etc.

Family attitudes -
Accepted
Passive
Rejected
Other attitudes

Sibling relationship

Behavior (before onset)

Home and Community Situation

Description of home
Economic, social, moral level
Type of neighborhood
(Factors rated according to description in running case record - Poor, fair, good)

School Situation

Type
Grade
Scholarship
School adjustment
(rated according to criteria reproduced in the appendix)

Hospital Adjustment

Diagnosis
  Date of Onset: Age of Onset:
Hospitalization
  Acute State
Recommendations
Observations of Staff

Environmental Situation to Which Child Was Returned:

Own Home:
  Former status
  Conditions altered, unaltered
Foster Home:
  Method of placement

Type of Adjustment

Home
School Situation (school or home teacher)
Community
Modification in behavior
Social factors affecting the adjustment

THE CLASSIFICATION OF PATIENTS

WITH

DISEASES OF THE HEART

Including patients with either organic cardiac disease or functional cardiac disorders

FUNCTIONAL CAPACITY

Class I Patients with cardiac disease and no limitation of physical activity. Ordinary physical activity does not cause discomfort.

Class II Patients with cardiac disease and slight limitation of physical activity. They are comfortable at rest but on ordinary physical exertion experience discomfort in the form of undue fatigue, palpitation, dyspnea or anginal pain.

Class III Patients with cardiac disease and marked limitation of physical activity. They are comfortable at rest but the above symptoms are caused by less than ordinary activity.

Class IV Patients with cardiac disease who are unable to carry on any physical activity without discomfort. Symptoms of cardiac insufficiency, or of the anginal syndrome, are present, even at rest.

THERAPEUTIC CLASSIFICATION

Class A Patients with cardiac disease whose physical activity need not be restricted.

Class B Patients with cardiac disease whose ordinary physical activity need not be restricted, but who should be advised against unusually severe or competitive efforts.

Class C Patients with cardiac disease whose ordinary physical activity should be moderately restricted, and whose more strenuous habitual efforts should be discontinued.

Class D Patients with cardiac disease whose ordinary physical activity should be markedly restricted.

Class E Patients with cardiac disease who should be at complete rest, confined to bed or chair.

POTENTIAL HEART DISEASE

Patients in whom no cardiac disease is discovered, but whose course should be followed by periodic examinations because of the presence or history of an etiological factor which might cause heart disease.

POSSIBLE HEART DISEASE

Patients with symptoms or signs referable to the heart but in whom a diagnosis of cardiac disease is uncertain.

(Classification ab stracted from criteria prepared by the Criteria Committee of The American Heart Association, Inc.)

C R I T E R I A F O R S C H O O L

A D J U S T M E N T

CHART I

CLASSIFICATION OF PATIENTS ACCORDING TO THE EXTENT OF PHYSICAL HANDICAP AT THE TIME OF THIS STUDY (1949) and SCHOOL ADJUSTMENT

CASE	MEDICAL RECORD CLASSIFICATION OF HANDICAP	SCHOOL ADJUSTMENT
R.R.	IA	PRE-SCHOOL
A.B.	IB	VERY GOOD
J.O.	IIC	VERY POOR
A.G.	IIC	GOOD
E.G.	IIIC	FAIR
J.M.	IIID	GOOD
E.H.	IB	POOR
D.H.	IIB	GOOD
K.M.	IB	GOOD
R.D.	IIC	FAIR
A.T.	IIC	POOR
J.O'N.	IIC	FAIR
C.R.	IIIC	FAIR
A.M.	IIC	GOOD
E.O.	IIB	POOR

CHART II

CLASSIFICATION OF AGE OF PATIENT AT ONSET
PROVISIONS FOR CONVALESCENT CARE AND
RELATION TO THEIR SCHOOL ADJUSTMENT

CASE	PROVISIONS FOR CONVALESCENT CARE	SCHOOL ADJUSTMENT
0-4 years, 11 months		
J. M.	Institution	Good
5-9 years, 11 months		
R. R.	Home	Pre-School
A. B.	Home	Very Good
J. O.	Foster Home	Very Poor
K. M.	Home	Good
A. G.	Foster Home	Good
E. G.	Institution	Fair
D. H.	Institution	Good
E. H.	Institution	Poor
10-14 years, 11 months		
R. D.	Institution	Fair
C. R.	Home	Fair
A. T.	Foster Home	Poor
J. O'N.	Foster Home and Institution	Fair
E. O.	Home	Poor
15-19 years, 11 months		
A. M.	Foster Home	Good

CHART III

FAMILY INCOMES OF PATIENTS STUDIED

Weekly Income (In Dollars)	Number of Children
65-69	0
60-64	2
55-59	0
50-54	1
45-49	0
40-44	3
35-39	8 ***
30-34	1
25-29	0
20-24	0
Total	15

B I B L I O G R A P H Y

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